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ABSTRACT

Intended for secondary school counselors, the pamphlet examines effects of epilepsy on course work and career planning. Briefly covered are the nature of epilepsy, treatment, social impact, and public misunderstanding. Effects on academic achievement are discussed in terms of functional problems related to where the seizure activity is located in the brain, side effects of medication, missed schooling, and effects of recent diagnosis. The pamphlet distinguishes among seizure-related behavior problems, social reaction behavior problems, and unrelated behavior problems. The need to avoid overprotection is stressed with guidelines offered for participation in driver's education, physical education, the athletics program, and industrial arts. Ways the counselor can help build a positive attitude toward career planning are suggested as is utilizing vocational rehabilitation services for graduating students more severely impaired. (DB)

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EC 211 047

Janie's bright, talented, popular. In her second year on the cheerleading squad. Did well on her PSAT's. Seldom absent. Works hard. Grades pretty steady. Active in the Spanish club as well as cheerleaders. Good kid all round. Now, let's see, why's she coming to the guidance office? Some problem with driver's ed, the note said. And what's this note on her file? That's a surprise. It says she has epilepsy.

★ ★ ★ ★

Everyone knows Marcie. She has a rough time of it. Bad skin. Talks so slowly, you want to push her along to get to the point. Has seizures pretty regularly, too. Some of the other kids call her "fall down, fall out." Pretty cruel, but hard to stop that kind of thing. Sometimes she has so many seizures you wonder if she really belongs in school. Other times, she's fine. It's too bad. She's intelligent, but her performance level is really uneven. Mother drives her to school every day, picks her up. Really keeps an eye on her. Wants Marcie to have easier courses next year, be less strain, she says. No plans for college, anyway. Going to live at home apparently. Mother may be right. . . . Wish there was something that could help, though.

★ ★ ★ ★

Joe hasn't been sent to the guidance office before, but, by the look of his file, it's surprising he hasn't been a regular visitor. . . . Barely passing in three subjects. Failing two others. In trouble for being "disruptive" in class. Some problem with fighting last month, too. He's taking the academic course . . . here's a letter from his father insisting that he take geometry, even though he only just passed Algebra I. Bright though, look at that I.Q.! Shouldn't be having problems with the work. A loner, it seems. No real friends. Poor social skills. And what's this over here? Oh, yes, he has epilepsy.

This booklet was produced by the Epilepsy Foundation of America with a grant from the American Legion Child Welfare Foundation.

Young people with epilepsy—three quarters of a million of them—are part of every school system in the country.

Like all young people, youngsters with epilepsy have individual talents and abilities, strengths and weaknesses. In general, their potential to achieve at school and succeed in life will not be limited by having this disorder. Advances in treatment mean more and more young people who have epilepsy can live normal lives and accomplish their goals.

Despite these positive developments, however, the youngster with epilepsy often has to cope with several unique problems at school. Unless these are understood by school personnel, and appropriate steps to counter them are taken, they may severely limit the student's scholastic and social development.

School counselors in particular can help:

- By learning more about epilepsy.
- By recognizing that it may vary in its effects.
- By helping students cope with any associated physical and social problems.
- By helping them plan their academic and vocational choices to achieve a satisfying and fulfilling future.
- By making other school personnel more aware of the nature of epilepsy and the potential of young people who have it.

The Nature of Epilepsy

Epilepsy is an umbrella term covering more than 20 different kinds of seizure disorder.

Generally, the person with epilepsy is in otherwise excellent health and does not seem to have any disability—except when a seizure occurs.

Having a seizure is the outward sign that the electrical system controlling the brain is not working properly. For a minute or so it produces a disorderly discharge of electrical impulses which may affect just one area or sweep through the whole brain to disrupt all physical and mental processes.

The result may be a convulsion, a brief stare, a period of confusion, uncontrolled movements, muscle spasms, automatic behavior or sudden falls.

Susceptibility to seizures may be produced in many ways—through injury to the brain, as a lasting effect of certain viral diseases, or by an inherited or acquired tendency to have seizures more easily than the average person.

Treatment

Today epilepsy can usually be treated successfully with regular use of seizure-preventing medication.

To be effective, this treatment requires the active cooperation of the patient.

This means that every day the teenager with epilepsy must take his medicine on time just as his doctor has ordered.

He may have to stay away from all alcohol use. He may have to be more careful about when he eats and how much sleep he gets than the average youngster his age. He may feel he is being "slowed down" by the medication.

Sometimes students rebel against the treatment by missing doses or taking less than prescribed.

Occasionally a youngster with epilepsy will even stop taking the medicines altogether. This puts him at risk of *status epilepticus*, non-stop seizures that require emergency treatment.

Young people with epilepsy need to see some tangible value in staying on the medicines. Sometimes a counselor (or a parent) can use the goal of staying seizure free to qualify for a driver's license as a way to encourage a youngster to keep taking his pills.

Social Impact

The social impact of epilepsy may vary according to how long the disability has been present. If a teenager has had epilepsy since early childhood, he may have been overprotected by well-meaning parents and have lost confidence in his ability to function on his own.

He may even have learned to use the possibility of having a seizure to get his own way at home and avoid work at school.

This kind of pattern is destructive in many ways. Fortunately, it can often be corrected by the counselor through meetings with the family, the student, and

sometimes with the assistance of an outside authority such as a counselor from a local epilepsy association.

In the same way, school guidance counselors can help the student with epilepsy (and his family) realize that he has to accept responsibility for his own success or failure in life.

Sometimes a teenager will try to hide the condition. Or he may turn a hostile face to the world in an effort to discourage name-calling. He may decide he'll reject others before they reject him.

His social skills may be lacking because his social contacts have been reduced. Low self-esteem may be reflected in careless dress and careless grooming.

Drug side effects may slow his speech or aggravate facial blemishes, setting him further apart from the other students.

If he has just recently developed epilepsy, he has to make the painful adjustment from being a person with no physical limitations to being someone who may have to take medicines for the rest of his life, someone who is not always completely in control of himself, someone who must deal with a society which often seems only too ready to restrict his activities and limit his ambitions.

Public Misunderstanding

Young people with epilepsy also have to deal with the fact that most people do not realize how much progress has been made in treating and understanding epilepsy. Many, including school personnel, still cling to the myths of the past.

For example, many people think that the only way to develop epilepsy is to be born with it. In fact, it can be acquired in many ways, particularly through head injury.

People often believe that having epilepsy is the same as having a mental illness or being mentally retarded. Again, this is not true. Each is a separate condition.

Teachers often have unrealistically low expectations of their students with epilepsy. Classmates may be afraid they will catch it (they can't), or be injured because of it (they won't), or that people who have it are likely to have seizures at any time (they aren't).

The fact is that at least 50 percent and perhaps as many as 85 percent of people who have seizures can get complete, reliable, long term control through cur-

rent therapy. That means months, even years, will pass without their having a seizure of any kind.

Academic Achievement

Having epilepsy is, by itself, no bar to high academic achievement. Many successful professional people—including writers, journalists, teachers, lawyers, and scientists—have epilepsy and have had no lessening in their intellectual powers or lowering of academic achievement.

A student with epilepsy who is doing well in his or her studies should therefore be encouraged to take demanding courses and to qualify for college entrance like any other student.

When a student with epilepsy is doing poorly, however, it is important to try to find out why.

Although students with epilepsy generally test within the normal IQ range, studies show many of them achieve at a lower level than expected.

When youngsters with high IQ scores perform substantially below expectations, family tensions of all kinds may result, especially if the parents are college educated with strong ambitions for their children. To them it looks as if the youngster is lazy and not trying.

But it may not be so simple. In fact, there are at least four possibilities for the counselor to consider when achievement is substantially below potential.

• **Functional problems may be related to where the seizure activity is located in the brain.** Epilepsy is a disruption in the way brain cells communicate. Since learning, processing information, and memory are all products of cell communication, it's not surprising that having epilepsy may sometimes be linked to disruptions of the learning process.

When the seizure area is in the brain's left temporal lobe, language, verbal skills and math may be affected, and so may skills like recognizing and remembering what is heard.

The problem may be intermittent, depending on whether a small, unnoticed seizure occurred at the time when key skills were needed—while doing homework, for example, or during a test.

The "off-on" nature of the disability adds to the puzzle, since the student sometimes does well and at

other times does very poorly.

Seizure activity from the right side of the brain can affect recognition of shapes and patterns. A student with this problem may misinterpret mathematical symbols and sometimes have a difficult time picking up on visual clues in social situations. He may also be clumsy and find sports activities difficult.

Young people trying to cope with this kind of disorder in their lives may become very attached to one way of doing things in an attempt to establish order. They may find it hard to adjust to change.

Special neuropsychological testing may identify some of these problem areas.

Knowing what is wrong helps teachers work out ways to minimize the problem. The fact that such disabilities exist need not rule out higher education since many colleges will make similar arrangements.

• **Side effects of medication.** The second possibility when achievement is lower than expected is that the student is being affected by the drugs that prevent his seizures.

Some medications have a sedative effect and may make it more difficult for a student to complete a timed test as quickly as his classmates. He may know the answers but take longer to think them out and write them down.

Having a medical re-evaluation, changing the time when medicine is taken (if the doctor agrees), or extending time available for a test, may all help improve the student's academic performance.

• **Missed schooling.** The third possibility to consider when academic performance is poor is the lingering effect of being absent from school in previous years. Treatment of medical problems and the need for tests and hospitalizations may have meant weeks off from school in the past.

A related problem results from previously undiagnosed absence (petit mal) seizures. These brief lapses in awareness may have gone on for years before a major seizure led to the epilepsy being recognized. Frequent breaks in attention may have seriously interfered with the learning process.

Young people who have had these experiences may lack the basic skills and understandings that everyone else got in the elementary school. Tutoring and summer school may help them catch up.

• **Recent diagnosis.** Sometimes a student who previously did well at school does poorly immediately after epilepsy is diagnosed. Epilepsy therapy requires careful tailoring of drug type and dose level. Sometimes even minor adjustments can produce major effects such as lethargy, mood swings, and a general feeling of discomfort. Later on, as treatment is stabilized and the youngster's system adjusts to the drug, academic performance usually improves.

Behavior

One of the persistent myths associated with epilepsy is that the person who has it will somehow go suddenly out of control and injure others.

Such a scenario is extremely unlikely. Still, students with epilepsy may turn up in the counselor's office with a record of one or another form of behavior that a teacher or other staff member has taken exception to. The counselor should look at these carefully and understand how they may relate to this particular condition.

• **Seizure-related behavior.** One type of seizure called a "complex partial seizure" produces automatic behavior that is easily misinterpreted as deliberate acting out or may be handled in such a way as to produce the appearance of a struggle.

This type of seizure is the most common form of epilepsy in teenagers and adults.

It starts with a blank stare, followed by chewing movements and picking at clothing.

Consciousness is suspended and the youngster goes through a series of almost trance-like movements. He may walk, or run, or shout, or bang on a table, or try to take off an article of clothing. He probably won't respond to teachers telling him to sit down (even if he looks at them in response to his name being called) because he doesn't know where he is or what is happening to him. For the minute or two that the seizure lasts he's out of touch with his surroundings and later on he probably won't remember what happened.

Behavior like this can easily be mistaken for deliberate provocation, or even drug or alcohol abuse. If someone grabs hold of the student while the seizure is going on he may strike out in a reflex action, at which point his behavior may be recorded as "fighting." A

gentle, guiding approach by a calm teacher can avoid this response.

It is therefore important for the counselor to know whether the "discipline problem" standing in his office may in fact be a youngster whose seizures take this particular form.

• **Social reaction behavior.** Having epilepsy puts severe emotional strains on young people because it produces temporary helplessness that often invites fear and ridicule. Treatment, as already noted, may restrict some activities. Isolation and loss of self esteem often results.

Students who've had epilepsy for a long time may have been teased and taunted for years, often by the same youngsters who now sit near them in high school.

If it's a relatively new condition, there is likely to be a potent mix of anger and grief at what has happened. The result may be an angry, hostile individual with a short emotional fuse.

Counseling and, if possible, contact with other young people with epilepsy through a local affiliate of the Epilepsy Foundation of America may help.

• **Unrelated behavior.** Occasionally a youngster with epilepsy may have brief periods of impulsive, aggressive behavior that are incorrectly assumed to be just another type of seizure.

In the overwhelming majority of cases such behavior is NOT related to the epilepsy. It is a separate problem which also occurs in youngsters who do not have epilepsy.

Mistaking a behavior control problem for a seizure may delay referral to counseling or other treatment that may help the youngster overcome the problem.

Avoiding Overprotection

One of the most difficult problems faced by adolescents with epilepsy is the well-meaning efforts of adults to protect them from harm by keeping them out of school and recreational programs in which injury might possibly occur.

This kind of exclusion keeps these young people from

acquiring the skills and having the experiences available to other youngsters. In some cases such action may even be contrary to the federal law (P.L.94–142) against exclusion of handicapped youngsters from school programs.

Although overprotection is a problem whenever it happens, there are certain primary areas of which counselors should be aware.

• **Driver's Education.** There is no reason why a youngster with epilepsy who can qualify for a learner's permit should be refused entry to the school's driver's education program.

All states allow people with epilepsy to drive after a period of time (between 3 and 24 months, depending on the state) in which they have had no seizures, and if their doctors will attest to that fact.

It should even be possible for a youngster who cannot yet qualify for a learner's permit to take the classroom and simulated driving part of the driver's ed package, leaving the road instruction for another time.

This kind of accommodation helps the student feel less isolated and makes the eventual attainment of a license more likely, since some states will only license young drivers who have had driver's ed at school.

• **Physical Education.** There are many kinds of physical education programs, and students with epilepsy should (with medical approval) be able to participate safely even if they are still having seizures if reasonable modifications are made.

There should be virtually no school-imposed prohibitions if seizures are fully controlled, although swimming and rope climbing should always be carefully supervised and the staff should always be aware that the class includes a student who has epilepsy.

• **The Athletics Program.** Few things are as devastating to a 16-year-old who has just developed epilepsy as hearing that it means he's off the team.

The decision may rest with the coach or the athletic department, or it may be school policy. Whatever it is, we would suggest that it be looked at very carefully to see whether an injustice is being done to youngsters whose athletic abilities are not affected by their seizure disorders.

If they have the talent to be on the team, and if the doctor agrees that they can compete safely, epilepsy should not be the factor that keeps them off. In gener-

al, vigorous physical activity is not associated with greater seizure frequency.

Professional and amateur sports have many participants who have been able to succeed despite having epilepsy. Basketball player Bobby Jones, pro golfer Roger Maltbie, triathlon winner Dave Horning, and ice hockey player Gary Howatt are all examples of this.

• **Industrial Arts.** Should young people with epilepsy be allowed to take "shop" courses that will teach them marketable skills but may expose them to moving machinery and the possibility of injury if a seizure should occur? Should criteria for entrance to the courses be based on the degree of seizure control?

These are difficult questions for school administrators, counselors, parents, and even the students themselves. Nobody wants to see students injured or running foolish risks. At the same time, it is important for all youngsters to have the opportunity to gain marketable skills or have access to skills which may be prerequisites to other academic pursuits.

The best answer is that there should be no blanket prohibition, and that each case should be evaluated individually. Careful attention should be given to the degree of seizure control, the type, frequency and time of seizures (if they're still occurring), whether the student experiences a warning before the seizure, and so on.

The possibility of adding other safety features to the programs to allow for greater participation by youngsters with epilepsy should also be looked at.

Career Planning

The good news today is that the majority of people with epilepsy are successfully employed in a wide range of jobs. The Epilepsy Foundation of America's employment services programs have helped thousands of people (some still having seizures from time to time) find jobs in such fields as advertising, design, bookkeeping, data entry, systems analysis, general sales, counseling, teaching, general administration, auto repair, landscaping, and many more.

However, there are some limitations. A student who is still having some seizures will have to avoid jobs that would require driving an automobile as part of the job (at least for the time being) since this would not be possible until his or her seizures improve. (In a few states people who have seizures only during sleep

are allowed to drive, but this is not the case everywhere.)

Students who have an occasional convulsive seizure or whose seizures take the form of brief lapses of attention a few times a day could do well in jobs in which there is time to compensate for a few lost seconds or minutes.

However, these students with occasional seizures would probably do less well dealing with unfolding events in which unrelieved concentration was needed.

When epilepsy is completely controlled, there are very few fields that are closed by law.

Closed occupations today tend to be mainly those in which an individual is solely responsible for the safety of others and in which a seizure could endanger that safety.

Piloting a commercial airliner, driving a large truck in interstate commerce, and joining the military (unless seizure free off medications for five years) are examples of the relatively few occupations from which people with epilepsy are officially barred.

However, the issue of safety on the job is one that students with epilepsy will want to consider carefully as their career decisions are made, both for their own well being and to avoid a disappointing job search.

Although most states have laws which forbid discrimination on the basis of medical handicap when the individual meets other qualifications for the job, these laws allow for contrary decisions if safety is clearly involved.

Federal regulations against discrimination by recipients of federal funds and by businesses which provide goods and services to the federal government likewise provide for rejection if a clear safety hazard exists or the disability interferes with the individual's ability to do the job.

For these reasons it is important that if a student is still having seizures occasionally and is not planning to go to college, his or her pre-graduation career planning should include a careful review of any limitations that the medical condition may impose.

Building a Positive Attitude

Sometimes the biggest barriers to employment for adults with epilepsy are their own feelings of hope-

lessness, built up by many years of disappointment and frustration.

Students can avoid these by seeking out and gaining successful job experiences while they are still in high school.

Students with epilepsy could be encouraged to join the Distributive Education Clubs of America (DECA) programs in high school, or sign up for similar student placement or work/study programs.

These programs can help develop good work habits and provide positive experiences of the working world. For young people with epilepsy, it's critical that such opportunities occur before negative thinking and low self esteem develop.

Another important element in helping a student build a good attitude is his own knowledge of the condition, his understanding of how it affects him, and his developing the confidence to talk to an employer about it in a way that will increase the chances of getting a job.

The Epilepsy Foundation of America (EFA) offers a unique employment service that helps people with epilepsy of all ages practice this kind of communication skill. It also provides job counseling and placement services.

The Foundation's Training and Placement Service (TAPS) project is offered in several cities nationwide in cooperation with the Foundation's local affiliates. Other affiliates may offer related employment services, counseling and social programs for young people as well.

The TAPS program and the local groups also provide in-service training to counselors, employment specialists, and school personnel.

Vocational Rehabilitation

Another source of potential help for the student with epilepsy who will be looking for a job after graduation is the vocational rehabilitation (VR) system.

This system, which is operated through the Rehabilitation Services Administration (RSA), is designed to help people whose disabilities represent a vocational handicap but who can be expected to find and retain a job after receiving its services.

Young people who are eligible can begin to use the system directly upon leaving school. In some states

eligibility begins at age 16 so that students can sign up while still in school.

The program is administered by the states, which can set their own priorities for service. Services for people with epilepsy therefore will vary. Epilepsy may have a higher priority in some states than in others.

Because of the variation, it is advisable for counselors to get to know the local system and the VR counselor in the local area so a judgment can be made on whether students in that community can benefit.

In some cases there may be VR funds to pay for college for the financially needy student with epilepsy if the agency decides that going to college is the best way to meet that student's vocational needs.

Students whose parents have financial resources above the cut off point may not be eligible for services that cost VR money (like job training or college, for example). They may still participate in counseling, guidance, and placement assistance, however, if they're otherwise eligible.

As this booklet indicates, having epilepsy often complicates life for the high school student and for the young graduate looking for a job after high school or college.

But there are ways to minimize its effects, ways to improve chances of success at school, at work, and in every day contact with other people. Thousands of people with epilepsy have learned to cope effectively with the challenges it offers. Often that process begins at school, with the help of caring, well informed guidance counselors.

Met with Mr. Byrce about Janie taking driver's ed. She's got to stay seizure free for just four more months before she can get her license. If she takes everything except the road test this semester, she'll get the driving experience from a private driving school over the summer. This arrangement should work out all round. Being able to drive will mean Janie can get an after school job next year.

★ ★ ★ ★

Met with Marcie's mother about her schedule next year. At first she wouldn't sign for the academic schedule. Doesn't want her daughter to go to college away from home because she's still having seizures. Turns out Marcie hasn't been evaluated by her doctor since she was ten. Just keeps taking the medicines prescribed back then—and sometimes doesn't take them at all. Says they make her feel dopey. Suggested Marcie be re-evaluated to see if seizures could be better controlled. Mother has agreed; in the meantime Marcie will continue with courses she'll need if later she decides to go to college.

★ ★ ★ ★

Joe's doing better since neuropsychological testing revealed that he has a functional problem with math. His father finally recognized that Joe's poor achievement in math wasn't just laziness, and has stopped pushing for him to take advanced classes. Joe's developed an interest in photography and is working on the year book staff. He's covering all kinds of school activities and is much better accepted than before. Mrs. Smith understands how to handle his seizures now, and he's had no more "disruptive behavior" reports. Things are looking up for Joe.

Suggested Readings

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For More Information

The Epilepsy Foundation of America and its local affiliates provide free information on all aspects of epilepsy. To contact the national office, write: Epilepsy Foundation of America, 4351 Garden City Drive, Landover, Md. 20785. To contact your local affiliate, write or call:

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